

Open Access Maced J Med Sci electronic publication ahead of print,  
published on November 27, 2017 as <https://doi.org/10.3889/oamjms.2017.205>

ID Design 2012/DOOEL Skopje, Republic of Macedonia  
Open Access Macedonian Journal of Medical Sciences.  
<https://doi.org/10.3889/oamjms.2017.205>  
eISSN: 1857-9655  
*Clinical Science*



# Kosovo's Experience for Children with Feeding Difficulties after Cardiac Surgery for Congenital Heart Defect

Ramush Bejiqi<sup>1\*</sup>, Ragip Retkoceri<sup>2</sup>, Hana Bejiqi<sup>3</sup>, Arlinda Maloku<sup>2</sup>, Armend Vuçiterna<sup>1</sup>, Naim Zeka<sup>2</sup>, Abdurrahim Gerguri<sup>2</sup>, Rinor Bejiqi<sup>4</sup>

<sup>1</sup>University of Gjakovo, Paediatric Clinic, University Clinical Centre of Kosovo, Prishtina, Kosovo; <sup>2</sup>Paediatric Clinic, University Clinical Centre of Kosovo, Prishtina, Kosovo; <sup>3</sup>Main Center of Family Medicine, Prishtina, Kosovo; <sup>4</sup>Medical School, University of Kosovo, Prishtina, Kosovo

## Abstract

**Citation:** Bejiqi R, Retkoceri R, Bejiqi H, Maloku A, Vuçiterna A, Zeka N, Gerguri A, Bejiqi R. Kosovo's Experience for Children with Feeding Difficulties after Cardiac Surgery for Congenital Heart Defect. Open Access Maced J Med Sci. <https://doi.org/10.3889/oamjms.2017.205>

**Keywords:** Cardiac surgery; Congenital heart defect; echocardiography; Chromosomal abnormalities; Feeding problems.

**\*Correspondence:** Ramush Bejiqi, University of Gjakovo, Paediatric Clinic, University Clinical Centre of Kosovo, Prishtina, Kosovo. E-mail: [rbejiqi@hotmail.com](mailto:rbejiqi@hotmail.com)

**Received:** 11-Jul-2017; **Revised:** 24-Sep-2017; **Accepted:** 27-Sep-2017; **Online first:** 27-Nov-2017

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**Funding:** This research did not receive any financial support.

**Competing Interests:** The authors have declared that no competing interests exist.

**BACKGROUND:** A feeding disorder in infancy and during childhood is a complex condition involving different symptoms such as food refusal and faddiest, both leading to a decreased food intake.

**AIM:** We aimed to assess the prevalence and predictor factors of feeding difficulties in children who underwent cardiac open heart surgery in neonatal period and infancy. We address selected nutritional and caloric requirements for children after cardiac surgery and explore nutritional interdependence with other system functions.

**METHODS:** This was a retrospective study in a tertiary referral hospital, and prior approval from the institutional ethics committee was obtained. Information for 78 children (42 male and 36 female) was taken from patients charts. Data were analysed with descriptive statistics and logistic regression.

**RESULTS:** From a cohort of analysed children with feeding problems we have occurred in 23% of such cases. At the time of the study, refusal to eat or poor appetite was reported as a significant problem in 19 children and subnormal height and weight were recorded in 11 children. Early neonatal intervention and reoperation were identified as risk factors for latter feeding difficulties or inadequate intake. Children with feeding problems also tended to eat less than children without feeding problems. There was a trend towards more feeding problems in patients with chromosomal abnormalities or other associated anomalies.

**CONCLUSION:** Feeding disorder is often and a frequent long-term sequel in children after neonatal or early infancy heart surgery. Patients with chromosomal and associated anomalies who underwent multiple cardiac surgeries are at risk of developing feeding difficulties.

## Introduction

A feeding disorder in infancy and during childhood is a complex condition involving different symptoms such as food refusal and faddiness, both leading to a decreased food intake. It often results from abnormal feeding development. Also, adequate nutrition is crucial and challenging for children after surgery for congenital heart defects. There is a worldwide reason for attention to the lesion or specific feeding problems, supplementation of trace elements and minerals, and an organised approach to pace, timing, and type of feeding are beneficial. These

patients need to be selected for preventive strategies, and nutritional intervention should be offered in order to increase the caloric intake of the child and to develop a sound feeding relationship in the family.

Babies with congenital heart defects often need more calories per day than babies with normal hearts, particularly if they are struggling with symptoms of congestive heart failure. Feeding can be challenging for some reasons, so parents and other caregivers often work closely with the baby's healthcare team to make sure the baby is getting enough calories to gain weight and grow [1, 2].

What is known?

1. Children with congenital heart defects have problems with feeding caused by heart insufficiency.

2. Patients with chromosomal and associated heart defects are at increasing risk for feeding problems.

What is new?

1. Patients with complex congenital heart defects and chromosomal anomalies who underwent multiple cardiac surgeries are at risk of developing feeding difficulties.

2. As a lack of paediatric cardiac surgeries in Kosovo, children with congenital heart defects have been surgically treated in many European and North American centres.

The aim of this retrospective study was to describe the prevalence of feeding disorders in infancy and children after open heart surgery.

## Material and Methods

The study included 78 children undergoing open heart surgery for congenital heart defects in the neonatal period and infancy between 2005 and 2010. The study group included patients who had survived more than three years after surgery; all patients who did not survive the first three years of life after surgery were eliminated from the study.

The study was designed collecting data from medical records of cardiologist diagnosis, reports from surgery intervention and outpatient correspondence as well as follow assessment three years after surgery from a paediatric cardiologist at tertiary level. In the lack of cardiosurgical services in Kosovo, all children were sent abroad for surgery. Cardiologist diagnosis from the local cardiologist was compared with diagnosis at the centre where the surgery was done, and there we found full compliance. Differently, from the other centres which used two years for reassessing the feeding behaviour, we have chosen three years as a reason that few children have been sent abroad under treatment with Prostaglandins where the possibility for developing neurological consequences is much higher. Otherwise, the period of 2 years is taken from more centres in the world as the ideal period to reassess feeding behaviour and only severe and relevant feeding disorders persist until that age, because the prevalence of the feeding disorders in the normal population has been well defined at the age of 2 years [7, 10, 11].

Analysed data included pre-operative data: birth weight, type of congenital heart defects,

associated anomalies and syndromes, need for giving Prostaglandins and long-term of treating, based on the type of CH. The Cardiac surgery data included: the centre where the surgery was done, the type of surgery, the duration of extra-corporal circulation or the duration of the operation in off bypass operations. Post-operative data included: duration of the mechanical ventilation, total hospital stay, in-hospital feeding parameters which included the duration of tube feeding, the onset of oral food intake, and whether the child was referred to the speech pathologist on account of severe difficulties in swallowing or sucking. In the post-operative data, we also have attached neurological findings documented during the routine neurological examination after the operation was labelled as neurological abnormalities.

To simplify data on cardiac defects included in the study, all these were divided into two groups based on cardiologist findings before the surgery and the intra-cardiac morphology during the surgery:

Group 1: "simple cardiac defects", in which a complete anatomical repair is possible by one intervention.

Group 2: "complex congenital disabilities" in which are necessary two or three cardiac surgery interventions achieve on anatomical or physiological repair.

Most patients from the Group 2 underwent two interventions and whereas few of them are preparing for third-stage of palliation.

Based on the age of children when they underwent surgery all patients are divided into three groups:

Group 1: Children underwent complete cardiac surgery on the neonatal period;

Group 2: Children where the first surgery was on the neonatal period and the second was in infancy;

Group 3: Patients where cardiac surgery was done on the period of infancy period.

The questionnaire was designed to obtain information for quality and quantity of the nutrition, on feeding behaviour and food intake, whether it was appropriate for the age of 3 years old. The questionnaire also includes body weight gain, needs for artificial feeding, present of gastro-oesophageal reflux and frequent respiratory infection (aspirate pneumonia).

Feeding disorder was defined as the presence of one or more of the following criteria at the age of 3 years, based on the information given by care provider.

Group 1: Child is partially or completely dependent on tube feeding;

Group 2: Feeding is not adequate for the following age and mostly is based on the drink or

takes pureed food;

Group 3: Child manifests delays in obtaining foods, there is a failure of thriving, the body weight is in the third percentile, child manifests anaemia etc.

In the absence of cardiac surgery service in Kosovo, all children were sent abroad. Based on the country where surgery was done, all children can be divided into four groups:

Group 1: Children operated in Italy (mostly Genoa, few of them in Bergamo, Padua, Bologna and Verona) – 54/78 (69 %);

Group 2: Children operated in Albania – 12/78 (15.4 %);

Group 3: Children operated in Turkey - 6/78 (7.7 %);

Group 4: Children operated in other countries - 6/78 (7.7 %).

### Statistical analysis

Data were analysed using the SPSS 15.0 for Windows statistical software. We analysed continuous variables which are expressed as the median (range) and dichotomous variables as numbers and percentage. Multivariate logistic regression analysis was performed to determine the independent influence of risk factors on abnormal feeding problems. Univariate analyses were performed using the chi-square test or Mann – Whitney U-test. Also, Spearman's correlation coefficient was calculated to determine the correlation between different risk factors.

## Results

The study group consisted of 78 patients. Median birth weight was 3.35 kilograms, with a range from 2.8 to 4.6; the median gestational period was 39 weeks (range from 32 to 41 weeks). The patients underwent surgery for CHD at a median age of 16 days, ranging from 8 to 27 days (Group 1), 18 days, ranging from 12 to 31 days (Group 2) and 5 month and 16 days, ranging from three months and 22 days to 7 months and 12 days (Group 3). Clinical signs of heart failure were presented in 43/78 (55 %) patients. Open heart surgery with the use of cardiopulmonary bypass was performed in 62 patients (79 %). The most frequent surgery was resection of the aortic coarctation 21/78 (27 %), large ventricular septal defect 17/78 (22 %) and arterial switch operation for transposition of the great arteries 13/78 (16.6 %) (Table 1). Malformations syndromes were present in 11/78 (14 %) children (Table 2).

Initially, feeding through the nasogastric tube was in 43/78 (55 %) children (all neonates and six infancies). After three years of feeding through the nasogastric tube, only three patients continued.

**Table 1: Type of congenital heart defect, number of patients and percentage**

	N	%
Aortic coarctation	21	27
Ventricular septal defect	17	22
Transposition of the great arteries	13	16.6
Tetralogy of Fallot	8	10
Complete atrioventricular canal	6	7.7
Pulmonary atresia with ventricular septal defect	5	6
Total anomalous pulmonary venous return	4	5
Double outlet right ventricle	3	3.8
Double inlet left ventricle	1	1.3

The remaining patients obtained a nasogastric tube on the introduction of the anaesthesia as a routine procedure to start early feeding within the first few post-operative days. None of them needed a gastroscopic tube.

**Table 2: Patients with malformation syndromes and with normal feeding, feeding disorders (FD) and neurological abnormalities (NA)**

	Normal	FD	NA
Trisomy 21	2	2	4
Microdeletion 22q11	2	1	0
Turner syndrome	2	0	0
Unclassified dysmorphic syndrome	0	1	1

### Feeding status after three years

From the study group of 78 children, nine patients (11.5 %) were diagnosed with feeding disorders. There was noted a strong relationship between the type of the surgery, duration of mechanical ventilation, age at the surgery, duration of perioperative tube feeding and centre where surgery was done (all  $R > 0.8$ ,  $p > 0.01$ ). Patients who undergo complex surgery (univentricular heart palliation, double outlet right ventricle), with small age at the time of surgery and longer ventilation were more frequent in the group with abnormal feeding compared with those with normal feeding behaviour. Also, patients with malformations syndromes manifested higher rate of neurological and feeding difficulties. The multivariate logistic regression analysis included the variables that were significant in the univariate analysis since there was a very high correlation between the three variables: type of CHD, age at operation and reoperation of the univentricular heart.

## Discussion

Retrospective analysis of the data of children who underwent open heart surgery shows that feeding disorders are a relevant problem in this population.

This study has not included all aspects of energy balance as we have not attempted to assess time spent and energy expended in activity, thermogenesis, or other non-resting metabolism. Using a similar definition of feeding problems and age of children at the time of the study, the prevalence of severe feeding problems is much higher in a population of children who underwent open heart surgery (23 %) in compare with healthy children (1.42 %) [4, 12]. This prevalence is almost as frequent and in correlation with age at the time of cardiac surgery and type-complexity of CHD. Cardiac defects are a significant constitutional factor which contributes to the development of defects in other organs and systems including secondary feeding difficulties. Simultaneously, our study shows that at the age of 3 years of feeding, difficulties were not depended from birth and gestational age, hemodynamic status pre and postoperatively but the greatest impact on the development of feeding disorders have general medical condition such are: age of children who go through the surgery, duration of the medical ventilation and type of surgery, reoperation. Since these three variables were strongly interrelated, only early feeding disorders and multiple surgeries remained significantly associated with feeding problems at the age of three years in the multivariate regression analysis [6].

Adequate enteral nutrition may be difficult to achieve early in neonates after cardiac surgery, but it is essential for growth, wound healing, and immune function. Feeding difficulties in infancy and childhood is a complex condition involving different symptoms, such as food refusal or inadequate intake leading to a decreased food intake and malnutrition. Child's feeding development is determined by its constitution, the environment and the child's learning process [3, 4]. Pathology in one or more of these components can lead to a feeding disorder. Factors of constitutional origin can be organic defects, such as defects of organs directly related to food intake or transport, or defects of other organ systems that disturb the child's feeding and digestion process by impacting on its general health [5]. The child's environment is defined by the parent's behaviour and the family's cultural and social background. Some children start with a purely organic problem, that is, constitutional or mixture of organic and non-organic components. Any imbalance between parental expectations and the child's feeding progress could cause an interaction problem, generating feeding disorders, such as food refusal, avoidance of aversion, on the part of the child. In most patients with feeding disorders, there are combinations of different factors that give rise to the disorder [6, 7].

Recent advances in cardiac surgery techniques and progress in the pre- and postoperative care of new-borns and low weighing children have substantially improved the survival of infants with CHD [8]. This trend is creating a growing "population at risk"

for neurodevelopmental and behavioural problems as well as for the development of feeding disorders. However, feeding disorders tend to be increasingly common since advances in technology are allowing more very ill children to survive.

Early identification of deficient oropharyngeal motor skills and vocal cord dysfunction is crucial to establish enteral nutrition safely and has been demonstrated to improve clinical outcomes. The use of prealbumin as a marker of nutritional state should be accompanied by C-reactive protein given the influence of inflammation on its levels. Insulin infusions may improve outcomes in patients with postoperative hyperglycaemia. Trace element abnormalities and early identification of immune-compromised states can aid in reducing morbidity in children after cardiac surgery. Use of feeding protocols and a home surveillance system for hypoplastic left heart syndrome improves outcomes of those children [4, 9].

Besides other relevant influences on the development of feeding disorders in our study the fact that children are treated in several different European Centres, mostly in Italian's, makes a significant implication and in some of the cases cardiovascular system was affected as a consequence of that some children have been longer treated by Prostaglandins (one 38 and the other one 36 days). From this, we can conclude that severe and long hypoxemia, caused by the primary defects and long-term Prostaglandin therapy are crucial for developing neurological and feeding abnormalities.

There was a high variability of the cardiac diagnoses in our study group. We found that univentricular repair was associated with a higher risk of feeding and neurological disorders in compare with simplex and at once corrected anomalies. This can be explained by the various degrees of intracardiac mixing and volume overload, various degree and duration of hypoxemia which is present in children with univentricular heart. These children often require palliative surgery within the first few days of life, followed by at least two other open-heart surgeries [13].

In our study the group with types of malformation syndromes was heterogeneous. It is known that not all syndromes are associated with feeding disorders; in our study in patients with trisomy 21 and those with microdeletion 22q11, the prevalence of feeding disorders is high, whereas in Turner's syndrome the prevalence is not present. The presence of feeding disorders in children with chromosomal and malformations syndromes are reported to be higher than in children without such syndromes due to the associated developmental delay, oral malformation and neurological comorbidity. In most children with malformation syndromes, several of the above-listed risk factors co-occur, which increases the probability of the manifestation and

persistence of a feeding disorder [14].

There is considerable inter-individual variability in the manifestation of feeding disorders within the same syndrome category. In our study group, children with chromosomal abnormalities had a higher prevalence of abnormal feeding development at the age of 3 years. The effect of malformation syndrome on latter feeding difficulties can also be mediated by other risk factors such as more complex cardiac defects and neurological comorbidity. The association between neurological disorders and feeding problems is a well-known phenomenon [8]. Neurological abnormalities such as muscular hypotonia are frequent in children with congenital heart defects and often are diagnosed before cardiac surgery [15]. Among those neurobehavioral abnormalities, there was also an absent suck or poor feeding efficiency. In our study, we found that neurological abnormalities at the time of surgery were associated with abnormal feeding behaviour at 3 years of age. This association persists after correction for other factors: children with neurological abnormalities were six times more likely to manifest later feeding disorders than those without neurological problems. Thus, confirmed neurological abnormalities before the surgery can contribute to the development of feeding disorders as an independent risk factor.

In conclusion, babies with congenital heart defects often need more calories per day than babies with normal hearts, particularly if they are struggling with symptoms of congestive heart failure. Feeding can be challenging for some reasons, so parents and other caregivers often work closely with the baby's healthcare team to make sure the baby is getting enough calories to gain weight and grow. Simultaneously, children who require cardiac surgery in the neonatal period and early infancy are at increasing risk of developing a feeding disorder at three years of age. This is a result of a complex multi-factorial process. Independent risk-factors include severity of CHD, the age of the child who goes through the surgery, type of operation and re-operation, duration of mechanical ventilation, previously diagnosed neurological abnormalities and presence of malformations syndromes. These factors provide key evidence as to which children need to be referred to multidisciplinary teams who will care for elimination or minimisation of feeding problems on these sensitive categories. Whenever feeding problems are reported, nutritional intervention should be offered to increase the caloric intake of the child and to develop a sound feeding relationship in the family.

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